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## The new normal

Esna Vermeulen is not your typical 15 year-old. This young girl has a strength and determination that belies her young age and slight frame.

Esna was born with a condition called Type 1 mixed fibre myopathy. This prevented her muscles from developing normally and also led to a severe curvature of her spine, called scoliosis. Because the spine grows at an unusual angle, the lungs are unable to work as they should and in Esna this resulted in a condition called respiratory acidosis.

“Due to my pre-existing muscular condition I had very low energy and when I was younger I had to wear hot, confining back braces to try and prevent my scoliosis from getting worse. As a pre-schooler I had a bit more energy, but

could never do any kind of sport that would injure my already-delicate spine.” During 2009 breathing became more and more difficult for Esna. She attributed her increased shortness of breath to her new back brace, because they were always tight and uncomfortable in the beginning. “I’ve always been a light sleeper waking up 3-5 times a night. I was just so tired and I thought my body decided to sleep deep. Little did I know that I had another medical condition called sleep apnoea where you don’t breathe properly or stop breathing completely when you sleep.” One morning in February 2010, Esna’s parents had difficulty waking her up. She was rushed to hospital and was admitted with a carbon dioxide level so high that doctors battled to get an accurate reading. Esna stayed in hospital for two months and then had to rely on a Continuous Positive Airway Pressure (CPAP) machine to help her breathe normally. “It’s my best friend. If I had to run out of a burning building this would be the first item I would grab.”

After being discharged from hospital, she immediately set her mind to the task of catching up with her Grade 7 work. “Unfortunately I had missed the trial period for being a leader but I wasn’t fazed. My goal was getting a scholarship to Uplands College, the most wheelchair- friendly school in the Lowveld. And I got it too! I learnt that it is okay to ask for help and not be totally independent, but I didn’t like it very much.”

“Grade 8 was awesome except for the pain getting worse. I had to go to physio twice a week or else I would be too stiff to work properly. I got an electric wheelchair in the first term and the school put up ramps for all my classes.” After Esna’s long hospitalisation she was no longer allowed to wear the confining braces. While it was a great relief to be free of them, her spine did become more and more curved until it resembled the letter S. Esna had what’s known as a double-curvature of the spine, with the top being curved at 90 degrees and the bottom at 131 degrees. Ordinarily people who suffer from scoliosis can have their condition corrected with braces, therapy and surgery, but Esna’s surgeon had always said that her bones weren’t dense enough to undergo surgery. Also her muscular and breathing conditions made surgery a whole lot more risky for her. Doctors in South Africa were understandably reluctant to do the operation because of the risk it posed to Esna’s lungs and heart. After her mom Karen did some research, she got in touch with the Head of the Scoliosis Research Society in America. He recommended Dr Robert Dunn in Cape Town.

“We went down to Cape Town and met Dr Dunn, who agreed to do the surgery after looking at my history. We also met Dr Sean Rogers who would

be my pulmonologist for the op and recovery.” Discovery Health Medical Scheme agreed to fund the procedure and the operation took place on 31 May 2013. Although Esna lost a lot of blood and Dr Dunn could not safely correct the entire curve of her spine, he managed to relieve the existing curvature. So much so that Esna has felt enormous pain relief since the operation. “I was so used to being in pain all the time, but I’m so happy now, because almost all my pain is gone. Also, my right lung is no longer collapsed, so I’ve got more freedom to breathe. It’s the most relief I’ve felt in years!” Esna’s dad Clinton credits Sharon Booyesen and Ineke Gietzman from Discovery Health’s Clinical Services Team with helping the family access the benefits they needed for Esna’s care.

Esna has, despite her incredibly difficult state of health, managed to consistently remain in the top of her class. She takes part in many activities such as orchestra, Cansa debutants, yearbook, the school newspaper and she’s a promising art student. She dreams of studying veterinary science, but because she does not have sufficient control of her muscles to complete strenuous surgeries, she hopes to become a research or forensic pathologist.

“Life is terribly unfair but everything happens for a reason and unfortunately life doesn’t stand still and wait for you. My mom was the first to use the phrase “the new normal”. Each time after something happens we have to get used to the new changes and carry on with life, fitting these changes into our routine, getting used to the new normal. Don’t dwell on how bad things seem right now; think of how you can work with/around what has happened to still reach your goals.” These are wise words from a little dynamo who will continue to make an indelible mark in the lives and hearts of all who meet her.

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### ***Discovery information***

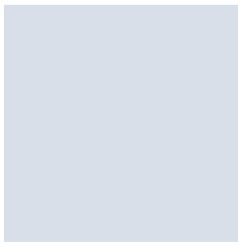
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